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# Providing Psychological Services for People with Diabetes

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## **Abstract**

Previous research and service development guidelines have highlighted the importance of psychological issues in diabetes care, and both people with diabetes and diabetes professionals recognise the need for specialist psychological input. This article outlines the development of a service delivery model for psychological services in diabetes care, based on a patient needs assessment and the advice of diabetes professionals. This involved an assessment of the psychological needs of people with diabetes within an urban Health Trust in Northern Ireland, and the collation of the views of local diabetes professionals.

Questionnaires to assess for depression, anxiety, binge eating behaviour and diabetes specific worries were completed by 300 people with diabetes. The participants were accessed through both primary and secondary care diabetes teams. As expected a high level of psychological distress relative to population norms was illustrated by the patient needs assessment. Particularly high levels of binge eating behaviour were reported, and levels of distress were higher for community managed patients than for hospital managed patients. The diabetes professionals unanimously agreed that there is a need for specialist psychological input and contributed to the service delivery model which is outlined in the article.

## Introduction

Medical advances in the treatment of diabetes have the potential to significantly improve clinical outcomes for people diagnosed with this condition. However many of these interventions depend upon lifestyle changes and behavioural restrictions, which are both difficult to achieve and to maintain. Difficulties have also been identified in the communication of such advice from health professionals to patients. Potential improvements in quality and quantity of life are threatened however by poor adherence to medical advice. Self-management is vital because poor glycaemic control can result in both micro and macrovascular complications. Behaviour change is complex and difficult to achieve and many clinicians report themselves to be ill-equipped to support the efforts of patients [1].

Diabetes is undoubtedly one of the most psychologically and behaviourally demanding of the chronic medical illnesses [2]. It is estimated that 95% of diabetes care is self-management [3], which involves various daily self-care behaviours and numerous lifestyle restrictions. Research demonstrates an increased prevalence of psychological distress among people with diabetes, most notably in the form of depression [4], anxiety [5] and eating disorders [6]. At both clinical and subclinical levels these difficulties have been shown to result in poorer diabetic control and increased complications [7]. Although we do not have a complete understanding of the interaction between diabetes and psychological distress, it is likely to operate at least partly through inhibiting adequate self-management. Whatever the specifics of this interaction, the indication is that

psychological interventions [may](#) have the potential to produce positive clinical outcomes, [although the necessary research is yet to be carried out](#).

There has been little research into the effectiveness of psychological interventions in diabetic samples, probably due to the lack of psychologists working in diabetes care. One small randomised controlled study found that Cognitive Behavioural Therapy (CBT) is an effective treatment for depression in people with diabetes ([ref?](#)). Existing psychological approaches to anxiety and eating disorders have not yet been shown to be efficacious within diabetes care. However some small scale studies have shown promising signs [8]. Psychological interventions have been shown to be superior to purely educational approaches in affecting behaviour change [on psychosocial outcomes](#). [9]. Despite the potential for improving self-management of diabetes, and physical and mental health, psychology remains under-utilised in diabetes care [8]. In Northern Ireland, service development guidelines have highlighted the importance of psychological issues in diabetes care and the current lack of attention to these issues [10]. These guidelines recommend ten times the current psychology provision for diabetes care in Northern Ireland and, along with Diabetes UK, recommend that a Clinical Psychologist should work as an integral part of diabetes teams.

This article outlines a piece of research commissioned by a Health and Social Care Group in Northern Ireland. The project aimed to establish the demand for psychological support in the population of people diagnosed with diabetes in South and East Belfast HSS Trust and to develop a service plan to meet these needs. The

project also assessed the potential for diabetes professionals to meet this need, and to provide a service delivery model based on these findings.

## **Methods**

### *Needs Assessment of People Diagnosed with Diabetes*

A sample of 300 people with diabetes resident in an urban area of Northern Ireland was obtained from both hospital diabetes clinics and through the diabetes registers of General Practitioners, [through opportunistic sampling methods](#). Males and females were equally represented in the sample; 39% of respondents had type 1 diabetes and 61% had type 2 diabetes. The higher proportion of people with type 1 diabetes came mostly from the hospital sample, which would be expected. The age of respondents ranged from 16 to 91 years, with a mean age of 55.4 years. The length of time since diagnosis ranged from 1 month to 44 years, with a median of 6 years. Participants completed questionnaires to assess the level of unmet psychological [need](#) and to assess the proportion of people who would like to have additional emotional support:

- The Hospital Anxiety and Depression Scale (HADS) [11]
- The Binge Eating Scale (BES) [12]
- The Problem Areas in Diabetes Scale (PAID) [13]

The PAIDS was slightly modified, so that respondents were asked if they would like to talk about each of the items, rather than indicating the degree to which each item is true. A response rate of 82% was obtained from the hospital clinics, although only 24% were returned from the GP lists. A poorer response was expected from the community sample as the questionnaires were posted.

### ***Needs Assessment of Diabetes Professionals***

An invitation was extended to diabetes health care professionals throughout the Trust, to attend a one-day seminar to discuss a service plan to meet the psychological needs of people with diabetes. A total of 118 professionals were invited to the seminar and 30 people participated in the seminar and discussion groups. The attendees at the seminar comprised of 6 hospital physicians, 2 dietitians, 3 General Practitioners, 2 podiatrists, 10 nurses, 1 ophthalmologist, 2 psychologists, 3 Health and Social Services managers and 1 representative from Diabetes UK.

The seminar began with a presentation of the findings of the patient needs assessment outlined above. Attendees were then separated into discussion groups and were asked to address the following questions, in order to guide the discussions:

1. Are the patients' responses in line with your expectations?
2. Do you feel that you are presently able to meet the needs expressed by patients?
3. What do you need in order to meet the needs expressed by patients?
4. How would you use a psychological support service for patients with diabetes?

Each group agreed a response to each question which was then recorded.

## Results

### *Needs Assessment of People Diagnosed with Diabetes*

The continuous data for depressive symptomatology and anxiety was collapsed into mild, moderate and severe categories, which indicate the severity of symptoms relative to population norms Almost one-quarter of the respondents demonstrated mild, moderate or severe levels of ~~depression~~ depressive symptomatology. This proportion was similar for people with type 1 and type 2 diabetes but hospital-managed patients had significantly lower levels of depression than that reported by community-managed patients [ $\chi^2(3) = 16.024$ ,  $p = .001$ ]. 41% of the respondents reported mild, moderate or severe levels of anxiety, and almost one-quarter of respondents reported moderate to severe levels of anxiety. There was no difference on anxiety scores between people with type 1 or type 2 diabetes or between hospital-managed and community-managed patients. However, females had significantly higher levels of anxiety than males [ $\chi^2(3) = 10.370$ ,  $p = .016$ ], with the majority of



females (51%) compared to one-third of the males experiencing mild, moderate or severe levels of anxiety.

The majority of the respondents (almost 81%) reported binge eating behaviour to some degree, with almost 30% of the respondents reporting severe binge eating behaviour. [Although the BES is not a diagnostic tool for eating disorders, a score in the severe category would indicate a level of disordered eating behaviour likely to significantly disrupt the individuals daily life.](#) A significantly higher proportion of people with type 1 diabetes compared to people with type 2 diabetes [ $\chi^2(2) = 8.502, p = .014$ ] and a significantly higher proportion of females compared to males [ $\chi^2(2) = 11.025, p = .004$ ] reported binge eating. When the interaction between diagnosis and gender is assessed, it becomes clear that the difference between males and females is only true for people with type 1 diabetes [ $\chi^2(6) = 22.108, p = .001$ ]. In fact 94% of females with type 1 diabetes engage in moderate or severe levels of binge eating behaviour. There was no statistically significant difference in levels of binge eating between hospital-managed and community-managed patients, but there was a trend for community-managed patients to engage in more serious levels of binge eating than patients sampled from the hospitals [ $\chi^2(2) = 5.690, p = .058$ ].

Respondents were asked if they would like to talk to a diabetes professional about any of 19 areas cited in the Problem Areas in Diabetes Scale. A total of 37% of community managed patients and 25% of hospital managed patients wished to discuss the relationship between mood and blood sugar levels. A higher proportion of community-managed respondents (than hospital-managed respondents)

expressed a desire to talk with a diabetes professional about all the problem areas identified on the questionnaire. About three times as many community-managed patients as hospital-managed patients wished to talk about not having clear and concrete goals for their diabetes care ( $p<0.001$ ), worries about low blood sugar reactions ( $p=0.001$ ), feeling overwhelmed by their diabetes regimen ( $p=0.007$ ) and not accepting diabetes ( $p=0.01$ ). When the respondents' diagnosis was taken into consideration it became apparent that these significant differences between hospital-managed and community-managed patients existed only for people with type 1 diabetes.

Patients' perceived support needs were assessed by the question 'How important do you think it is that people with diabetes have easy access to a member of staff to get help with problems like [items in the PAIDs]'. Approximately 95% reported that this would be important and the majority (67.4%) thought it was very important. Respondents were also asked 'If you had access to a member of staff to get help with problems like [items in the PAIDs], how much would that improve your satisfaction with the care you receive?' Three quarters reported that their satisfaction with the care they receive would improve, and the majority (51.5%) reported that it would improve a great deal.

### ***Needs Assessment of Diabetes Professionals***

The main themes recorded within the group discussions were as follows:

- Most expressed concern at the levels of psychological distress experienced by people with diabetes
- There was a clear consensus that professionals involved in diabetes care do not currently have the capacity to meet the psychological needs of the patient group, mainly because of a lack of time.
- Nurses tended to be more aware of the high levels of distress experienced by patients
- Some were surprised at the level of anxiety reported by the patients, as their understanding of poor adherence had centred on 'not being anxious enough'
- They agreed that psychological support for people with diabetes is important and can impact on their medical outcomes but they do not have the time or resources to address emotional issues at the level required. A few health professionals felt that it may not be appropriate for them to meet the emotional needs of the patients – that was someone else's responsibility.

The following suggestions were made for future service provision, in relation to the psychological care needs of people with diabetes:

- A psychological service to whom the professionals could refer patients, from both the hospital and the community
- Training for healthcare professionals from psychologists in the management of patients' emotional needs. Including specific issues such as identifying binge eating behaviour, understanding patient motivation and broaching sensitive matters (e.g. sexual problems)

- The need for training of health care professionals to identify what emotional needs of the patient they could deal with and what types of emotional needs should be referred to specialist help. In conjunction with this, there would be a need to establish guidelines and a clear referral pathway to psychological services.
- Recognition by employers that the focus of the work of the health care professional needs to be expanded to include formal consideration of patients' psychological needs, with appropriate time and resource allowance for these duties.
- Psychologist should work as an integrated part of the diabetes team.
- Behaviour change workshops for patients and support for families of people with diabetes
- Psychological support for staff.
- The establishment and funding of peer support groups and a helpline
- An improvement of links with local voluntary groups.

### A Model of Service Delivery Discussion

The current study adds to the body of existing research which indicates elevated levels of psychological distress in people with diabetes. The prevalence of depressive symptomatology (25%) is similar to that reported in earlier UK studies [14]. Significant levels of anxiety were reported by 41% of the sample, and this problem is unlikely to be properly managed in a situation where poor adherence to medical advice is often construed to indicate low levels of anxiety. Both depression and anxiety are amenable to psychological intervention, most

notably Cognitive Behavioural Therapy [15]. Research has not yet been carried out to specifically assess the efficacy of CBT for people with concurrent diabetes, although there are no apparent contraindications and clinical experience indicates that this effect does generalise to people with concurrent diabetes.

The majority of respondents (81%) reported a ~~worrying~~significant? degree of binge eating behaviour, with almost 30% of the respondents engaging in severe binge eating behaviour. Binge eating is now considered as being a specific category of the eating disorders, which is associated with obesity. Binge eating differs from overeating in that it involves a loss of sense of control over eating and is associated with negative emotions such as self-disgust. Approximately 95% of females with type 1 diabetes in this sample reported severe binge eating behaviour. This level of disordered eating poses a health risk in itself, and becomes more dangerous when accompanied by diabetes. Although these levels of binge eating behaviour in people who have diabetes have yet to be replicated, these findings suggest that the prevalence of eating disordered behaviour in this population has not been fully appreciated. Disordered eating behaviour ~~also~~ requires specialist psychological intervention and such a high prevalence of binge eating behaviours could only be addressed by disseminating appropriate psychological knowledge to ‘front-line’ healthcare professionals.

A finding which has not been explored in previous research is that the community-managed patients in the present sample displayed significantly higher levels of depression than hospital-managed patients. Levels of depression were not significantly different across type of diabetes, but a greater prevalence of

depression was found in the community sample. Despite lacking a full understanding of the reasons for this trend, this finding has immediate implications for the provision of diabetes care across primary and secondary care. The importance of this finding is magnified, as the proportion of people with diabetes being reviewed in primary care is increasing [16].

Both patients and professionals indicated a need for psychological input into diabetes care. Increasing numbers of clinical psychologists are now being employed within health teams in the NHS, specialising in areas such as chronic pain, cancer and diabetes. Psychologists in diabetes have a multifaceted role, both disseminating core skills and evidence-based approaches to other professionals, and providing a higher level of skill required to tackle more complex cases. There is evidence to show that incorporating simple psychological interventions into the practice of health professionals improves both medical and psychosocial outcomes [17], thereby suggesting an important training role for psychologists. However, other evidence suggests that interventions focusing solely on changing the consulting style of professionals are less effective than those focusing on the behaviour change of patients, and that improving the provider-patient relationship requires intensive and continual support [18]. Consequently, the provision of a specialist psychological service for people with diabetes could prove to be a long-term cost-effective option. [Recent developments have also included increasing numbers of other professionals equipped to provide psychological care, such as Cognitive Behavioural Therapy Nurses and Graduate Mental Health Workers, who would become an invaluable part of any such service.](#)

Based on the significant level of unmet need reported, and consultation with a range of healthcare professionals involved in diabetes care, a service plan was developed. This entails a specialist psychological service for diabetes care, serving both hospital and community based diabetes clinics. As well as providing direct intervention in complex cases (for example, when personality factors are affecting ability to self manage diabetes). This service would also be responsible for training and supporting other members of the diabetes team in behaviour change skills and providing emotional support. A third level of intervention would involve providing group training for patients in behaviour change and co-ordinating peer support initiatives.

Such a dedicated service would provide patients with the continuity of care they need, enhance their satisfaction with their care, address their emotional needs and improve their adherence and co-operation with the prescribed medical regimens. Despite employing a relatively small number of psychologists, within this model psychological therapies would reach large numbers of patients, and provide appropriate support for staff. Healthcare professionals tend to have a natural propensity to provide emotional support, and this would be harnessed by training in psychological methods and supported by appropriate staff care. There is a need for more research on psychological interventions in diabetes care, but it seems unlikely that high quality outcome research can be carried out until psychological care in diabetes is adequately resourced and becomes an integral part of diabetes care.

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## **Key Points**

- High prevalence of psychological distress among people with diabetes, and this is associated with poorer diabetic control
- Psychological knowledge and skills are under-utilised in diabetes care
- Psychological therapies can be provided cost-effectively through a specialist psychological service providing direct interventions in complex cases, alongside staff training and support
- People with diabetes see psychological care as a priority for service development

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